Title of Article

In the Cloud of Cannabis: Caring for people with multiple sclerosis who use cannabis for symptom control.

Author 1 and corresponding author

Laura Daly

Research Assistant

Queen Margaret University Edinburgh

LDaly@qmu.ac.uk

Author 2

Caroline E Gibson

Senior Lecturer in Nursing

Queen Margaret University Edinburgh

cgibson@qmu.ac.uk

Author 3

Professor Jan Dewing

Sue Pembrey Chair in Nursing

Director of Centre for Person-centred Research Practice

Queen Margaret University Edinburgh

jdewing@qmu.ac.uk

Total word count- 4385 (Not including PRISMA and Table)

Abstract:

Research to-date suggests a large proportion of people living with MS are using cannabis as a way to self-manage symptoms, and, if not, believe that there are potential benefits in using this drug. Community nurses are frontline caregivers; therefore, it is likely they will come into contact with people who use cannabis for MS within the home setting. The literature base surrounding this topic is largely driven by quantitative research examining the effectiveness of cannabis as a medicine. This review has found that qualitative research exploring the experiences of people who use cannabis for MS is lacking around the world and is completely absent within UK nursing literature. Persons using cannabis for MS, in some cases, do not feel safe in discussing this with healthcare professionals through fear of being judged. This literature review discusses how people perceive the effectiveness of cannabis in helping symptoms associated with MS while also drawing upon stigma and legal concerns people face. Community nurses will gain more understanding of social/ political issues and how this influences the decision to use cannabis. The findings from this review will help community nurses inform their practice and enhance person-centred relationships between nurses and persons living with MS.

Keywords: cannabis; community nursing; multiple sclerosis; person-centred; symptoms; stigma

Introduction:

Around 100,000 people in the United Kingdom (UK) live with Multiple Sclerosis (MS) (MS Society, 2017). MS is a neurodegenerative condition whereby the immune system attacks and breaks down the protective myelin sheath surrounding the nerve fibre (Goldernberg, 2012). This can result in varying degrees of disability. Nerve signals can become distorted or neurotransmission does not occur at all. With increased survivorship for long-term conditions, people can live with symptoms for many years, and, in some cases, this will result in a decreased quality of life (Kesselring, 2005; George & Martin, 2016).

Conventional treatments for MS usually include steroids and disease modifying therapies, (Chong et al, 2006; Minagar, 2013) to decrease the number and/or severity of relapses (Fox & Rhoades, 2012). The use of complementary and alternative therapies for MS is on the rise within the UK and other countries around the globe (Skovgaard et al, 2012). In a survey conducted by the MS Society, it was reported that one in five people who have MS use cannabis as a complementary therapy and as a means of self-management (MS Society, 2017). However, Sativex, a cannabis-based medication for the management of symptoms related to MS was discontinued in 2014. NICE recommended that doctors should not offer this medication because it is deemed not cost effective. However, research does show it is effective in treating symptoms such as spasticity (Serpell et al, 2013) and neuropathic pain (Russo et al, 2016).

Community nurses are caregivers with a commitment to promote wellbeing amongst vulnerable persons and to support and empower people including those in lay caregiving roles to participate in decision-making around their care (QNIS, 2015; NMC, 2001). However, for nurses working with people with MS in the community, who use cannabis for symptom control, there is little evidence to support and inform practice. This article was stimulated by personal reflections from the first author while meeting people who use cannabis for MS symptom relief, during a visit to a centre which supports people living with this condition. Moreover, learning derived from an undergraduate honours dissertation project sparked further interest in this topic.

What follows is a critical review of the literature of some issues relevant to the practice of community nurses working with people who have MS and are using cannabis; with the potential to influence more person-centred working. Person centred-practice is central to nursing and is underpinned by shared-decision making, being sympathetically present and acknowledgement of personal values regarding person-centred care (McCormack & McCance, 2017). Care that is safe, effective and person-centred is central to UK government policy and strategy such as the Care Quality strategy (2016) (Scottish Government, 2016). Person-centredness is both a way of working and being in which nurses help people to maintain or enhance their identity and wellbeing (McCormack & McCance, 2017). Person-centred practice requires the space for risk taking and innovation (McCormack and McCance 2017) and this is more challenging where there is an unclear evidence base to inform decisions.

Cannabis

Cannabis (*Cannabis Sativa*) is a flowering plant which contains around 400 chemicals, over 70 of which are cannabinoids (Atakan, 2012). Two of these cannabinoids have been of interest within the field of medicine- THC (Tetrahydrocannabinol) and CBD (Cannabinol). THC is the psychoactive substance, which produces the feeling of a 'high' while CBD contains no psychoactive properties. Cannabis can be consumed in four main ways; smoking, eating, vaping, using oils distilled from the plant's compounds and topical creams and lotions (Barrus et al, 2016). Persons using cannabis for symptom control may choose one or more of these methods of ingestion; and the potency of THC and/or CBD will vary, depending on product and person (i.e. their personal preference for product, ingestion and tolerance). Confusion can arise when discussing cannabis for medical use. 'Cannabis for medical use' could mean both legal cannabis-based products and illicit cannabis used for the management of symptoms related to a particular condition/illness. The use of medicinal cannabis has been at the centre of public and political debate over recent years, gaining the attention and interest of many researchers, but not without raising controversy, mainly around whether legalisation for
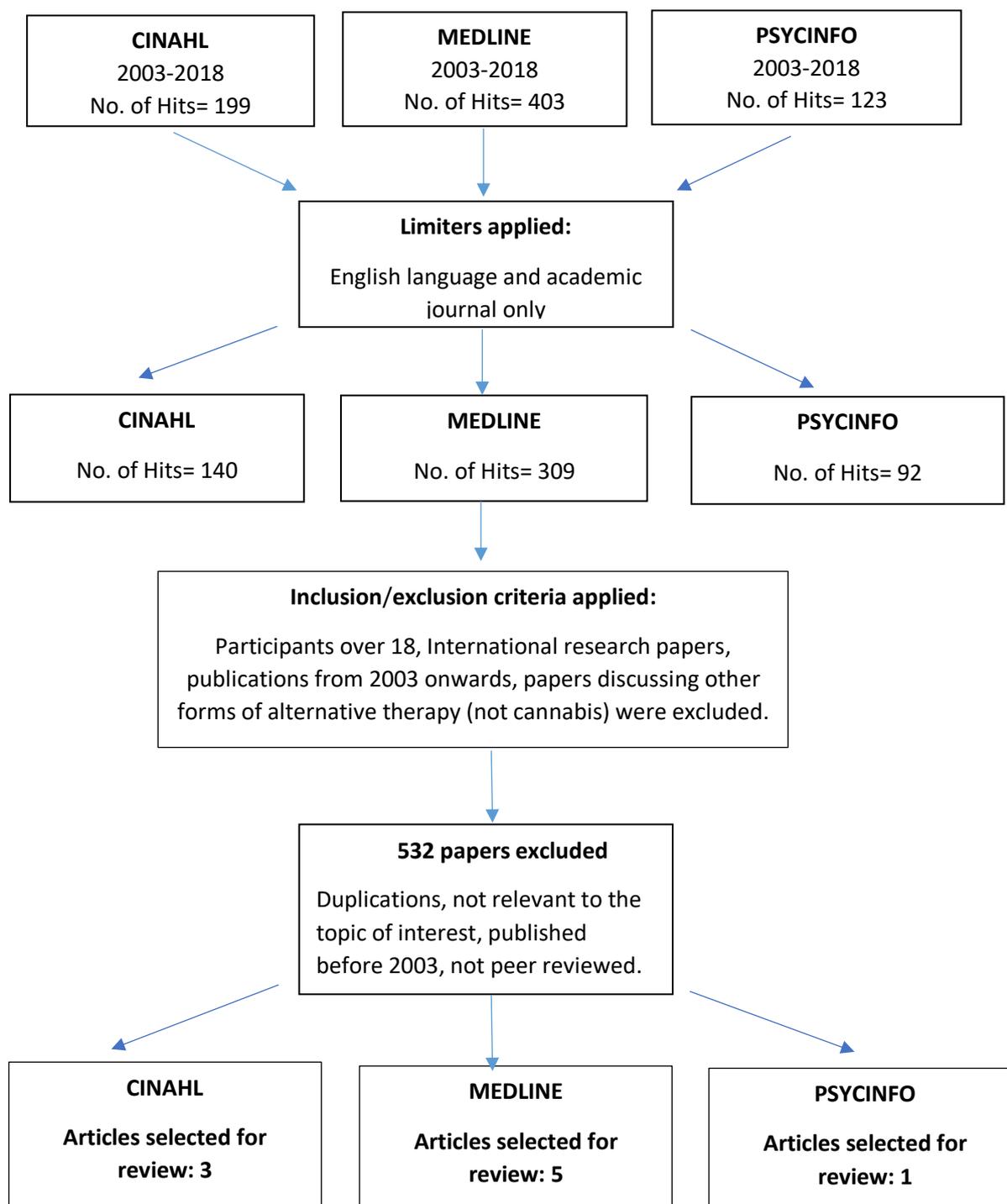
medical use should be permitted (Bonn-Miller et al, 2014; Troutt and DiDonato, 2015; Sexton et al, 2016). There has been an abundance of published literature exploring the effectiveness of cannabis as a medicine in helping to alleviate some symptoms associated with MS. However, from a scoping search, conducted by the first author, it appeared that most research undertaken within the UK is quantitative in nature, thus relating to the application of certain methodologies, methods and processes in the conduct of the research (Zajicek et al, 2005; Sexton et al, 2016; Kindred et al, 2017). Undoubtedly, this is useful for providing numeric and evaluative data relating to the effectiveness of cannabinoids; although it does not pay great value to the 'patient voice' (Austin & Sutton, 2014). To explore the gap further, a systematic literature search was conducted, by the first author. In this review, it became clear that internationally, qualitative research, such as that investigating the experiences of persons with MS who use cannabis as a means of coping and leading an active life was minimal (Bottorff et al, 2013; Page & Verhoef, 2006; Banwell et al, 2016); and completely absent from UK nursing literature. We focus on the findings from the systematic review for the rest of this article.

Literature Review:

A literature search was conducted in 2018 to identify what is currently known about the experiences of people who use cannabis to manage symptoms associated with MS.

The databases Medline, PsycInfo and CINHAL were used. Nine publications from four countries were included in the final review and included cross sectional surveys and qualitative interview methods. (See appendix 1). Search terms used were cannabis OR medical marijuana AND experience OR perspective. The PRISMA model was used to record the key aspects of the search and retrieval. (See the adapted PRISMA table in diagram 1).

Diagram 1. PRISMA

CINAHL 2003-2018 No. of Hits= 199	MEDLINE 2003-2018 No. of Hits= 403	PSYCINFO 2003-2018 No. of Hits= 123

Limiters applied:

English language and academic journal only

CINAHL No. of Hits= 140	MEDLINE No. of Hits= 309	PSYCINFO No. of Hits= 92

Inclusion/exclusion criteria applied:

Participants over 18, International research papers, publications from 2003 onwards, papers discussing other forms of alternative therapy (not cannabis) were excluded.

532 papers excluded

Duplications, not relevant to the topic of interest, published before 2003, not peer reviewed.

CINAHL **Articles selected for review: 3**	MEDLINE **Articles selected for review: 5**	PSYCINFO **Articles selected for review: 1**

The significant finding was the absence of UK based qualitative research that discussed experiences of people who use cannabis for symptom control. Due to a growing momentum for drug policy reform cannabis for medical purposes has recently been permitted by UK government (GOV UK, 2018) for use within certain conditions. This may influence further

research in the topic. However, people cannot yet easily gain access to cannabis based medications through GPs and other healthcare professionals and may turn to, or, continue to access cannabis through other sources; making research more challenging. UK Government has stated that further research will be undertaken to distinguish what constitutes a medical product, dosing and long term-effects (GOV UK, 2019). From reading through the selected literature in this review, three themes were identified: i) perception of efficacy of cannabis among people with MS, ii) experience of associated stigma and iii) legal concerns among people with MS. These will now be discussed.

Perception of efficacy of cannabis among people with MS

A range of empirical research (Zajicek et al, 2012; American Academy of Neurology, 2014), anecdotal reports (Hornby & Sharma 2010) and case studies (MultipleSclerorsis.net 2018) regarding the use of cannabis among people with MS, have indicated that many people find this drug effective in the alleviation of symptoms such as sleep and mood disturbances and continence deterioration. The Cannabinoids in Multiple Sclerosis study (CAMS) (Zajicek et al, 2003) was the first UK randomised placebo-controlled trial which aimed to evaluate the effectiveness of cannabinoids for treatment of spasticity and other symptoms related to MS. Of 630 participants recruited, 611 followed up to the primary end-point did not have any treatment effects on the primary outcome (change in overall spasticity score on the Ashworth sale). Although this study did not gain statistically significant results, subjective improvements were reported amongst 61% (n=121) of the cannabis extract group, 60% (n=108) in the group receiving THC and 46% (n=91) in the placebo group. Reasons for this improvement are unclear and it is interesting that almost half of those in the placebo group perceived a benefit, perhaps illustrating the advantages of participating in a research study (the placebo effect) (Rajagopal, 2006). However, the CAMS findings correspond with results from other studies examining the usefulness of cannabis as a medication. Trout & DiDonato (2015) created an online survey and used purposive sampling at government registered cannabis dispensaries within Arizona, US. The aims of this study were to describe participant characteristics,

perceptions and impressions of medical cannabis use and legalisation. Although the sample was made up of a population with diverse medical conditions, five people with reported MS were included and 130 people with reported muscle spasms. It was found 100% of participants with MS reported general relief associated with using cannabis and 75% stated they gained relief compared with other medications. In addition, 85.4% of all participants (n=367) reported they felt 'somewhat more confident or much more confident' in knowing that they had purchased a safe and uncontaminated product. Indicating the importance of medication safety as a key concern.

The CAM and Arizona studies both indicated a high percentage of people with MS who felt they benefitted from cannabis use, although overall validity in the latter can be questioned for a number of reasons. For example, inclusion and exclusion criteria were not discussed which means that anyone who used dispensaries within Arizona and had access to the internet could have been included in the study sample. This influences the reliability of the results in relation to persons with MS. However, another study (Kindred et al, 2017) also produced similar findings. A strength of Kindred et all's (2017) large study is that it explicitly stated the websites to which the survey hyperlink was uploaded, thus ensuring the researchers knew where recruitment took place (MS Society and Michael J Fox Foundation websites) which increased rigour. The survey remained online for eight months and was viewed 801 times with 595 participants included in the final data set. The majority of participants (76%) reported living with Parkinson Disease (PD) and 24% with MS. Arguably participants with PD were over-represented within the study and findings may not reflect the experiences of persons with MS. Cannabis use was reported in 44% of participants, with 74% of this group declaring it was for medical purposes only. Current cannabis users gained lower scores within the Guys Neurological Status Scale, specifically in memory (p=0.30), mood (p=0.002) and fatigue sections (p=0.009). An interesting finding was people with MS found cannabis more effective in symptom management than respondents with PD (p=0.002).

In summary, only one study demonstrated statistically significant findings about the influence of cannabis (Kindred et al, 2017), in relation to its effects on memory, mood and fatigue.

However, many participants perceive they are receiving benefits from the use of this drug, which is likely to influence their use of it. The research papers all declare a need for further research in the efficacy of cannabis as a medicine. While most research has been undertaken in the US and Canada where, in some areas, cannabis is now legalised for medical use, there is a need for more research within the UK to better understand how people living with MS experience the effects of this drug, their patterns of use and the challenges they face.

<u>Experience of associated stigma</u>

As there is currently a blurring of what constitutes a medical cannabis product in the UK (MS Trust 2018) people using cannabis for the relief of symptoms associated with MS could be subject to potential stigma. Stigma and the associated judgement can have a powerful impact on the way people interact with others and therefore may influence whether cannabis use is disclosed to the community nurse (Satterlund et al, 2015). Illicit drug users, for example, report experiencing a level of discrimination due to the labelling of this being a lifestyle choice (Sleeper & Bochain 2013). As a result these individuals have been found to receive a poorer quality of healthcare (Luoma et al, 2014). Around the same time, Bottorff et al (2013) reported that persons using cannabis for medical purposes experienced stigma. They attributed this to three reasons: cannabis is considered a recreational drug, current criminal penalties are associated with its use and cannabis is associated with vulnerability (current illness and level of disability). With regard to social stigma one participant stated:

> *"Nobody turns around and says you're a junkie if you have terminal cancer and are on heroin. But it doesn't matter why you're on marijuana, if you're on marijuana "you're a pothead and get the hell away from me." (Bottorff et al, 2013, pg. 4)*

This highlights that people can face judgement from the use of this drug although potential benefits are present. Moreover, Bottorff et al (2013) identified that those who used cannabis would attempt to keep this private from others. One participant said:

9

> *"Keep your mouth shut, grow it, use it, don't tell anybody, don't even tell your family, don't tell your friends, keep it to yourself and save your own life."* (Bottorff et al, 2013, pg. 6)

Research conducted by Page and Verhoef (2006) found that participants talked of 'testing the waters' to gauge how healthcare professionals would react. One participant highlighted:

> *"It took me a while just because I wasn't sure of what their reaction would be. So, you just sort of slide little things in here and there."* (Page and Verhoef, 2006, pg. 69)

If a negative attitude was anticipated, information regarding use was not divulged. Bottorff et al (2013) provide rich and detailed accounts of conversation from the interviews and direct quotes were included in the paper, thus increasing the research trustworthiness and authenticity. Participants were recruited through four British Columbia community-based cannabis dispensaries and an online forum for medicinal cannabis. This study included participants living with other conditions such as cancer, which means that the findings may not necessarily reflect the experiences of persons with MS. Further, two participants with neurological disorders were included without the researchers explicitly stating what these were. Data were collected through semi-structured face-to-face or telephone interviews as the researcher wished to gain an in-depth account of personal experiences. This may have been beneficial as it may have afforded the participants anonymity to discuss cannabis use openly. However, telephone interviews can also result in the absence of visual cues, loss of non-verbal data and may compromise rapport between interviewer and interviewee, therefore affecting data interpretation and dependability of findings (Novick, 2008).

Page & Verhoef (2006) interviewed people with MS in order to describe medical cannabis use from their perspective. Participants (six men and eight women) responded to a survey, which was mailed to a sample of 780 persons who attended an MS clinic in Calgary. The paper reports data saturation was reached, i.e. participants were interviewed until there was no new

information found, therefore increasing trustworthiness of the findings (Saunders et al, 2017). The perceived effects were associated with a sense of relaxation and relief of specific symptoms although some participants described negative side effects such as fatigue and balance problems. Participants reported keeping their use of cannabis private through fear of judgement from others and resonates with the conclusions of Bottorff et al (2013). The findings also correspond with those of Banwell et al (2016) who noted that 14.1% of participants stated their feeling toward a friend would change if they discovered they were using cannabis. Furthermore, 28.6% stated they would feel uncomfortable if people around them were using cannabis. These findings are particularly interesting as participants involved in this study all had a clinical diagnosis of MS and indicates that some people's feelings would change towards a person using cannabis. While these studies were conducted in the US and Canada their findings are likely to be applicable to the UK context where cannabis for medical purposes has recently been permitted. In summary, it could be suggested that people living with MS who use cannabis can potentially experience judgement from others. Bottorff et al (2013) did represent strong findings in relation to this, however failed to state explicitly if people with MS were involved in the study, therefore may lack applicability to this population. Due to the recent change in law in the UK further research should be conducted in order to learn more about possible social stigma which has been shown to surround cannabis use and how people experience and cope with this.

Legal concerns among people with MS

The MS Society report (2017) highlighted that a large proportion of persons with MS use cannabis for symptom control, and many more are familiar with the potential benefits for their condition. However, due to a level of confusion regarding the recent change in legislation in the UK (Torjesen, 2018) alongside the illegality in other countries around the globe, some people choose not to use this drug through fear of prosecution or other legal or social sanctions. Chong et al (2006) explored the extent and patterns of cannabis use in South-East London using a cross sectional survey method and found that 71% of people with MS who

had never tried cannabis would be willing if it was available to them on prescription. These findings concur with those of Page et al (2003) who found that 96% of participants were aware of the potential benefits of using cannabis for their symptoms. Of participants who were aware of these benefits but had not tried the drug (n=222) the most significant reason given for not doing so was legal concerns (64%). The study also found 35% (n=67) of participants had tried cannabis at some point in their life in an attempt to manage symptoms and 8 people discontinued as a result of legal fears. A questionnaire was used to gather data, with the inclusion of a comments section enabling participants to elaborate further on their perceptions. This triangulation is advantageous to data collection in that it draws on more than one method in order to display a more accurate representation of findings (Carter et al, 2014). Both Chong et al (2006) and Page et al (2003) found many participants in their studies expressed eagerness for the legalisation of medicinal use in order for them to safely control symptoms and self-manage this condition.

A retrospective study (Martinez-Rodriguez et al, 2008), conducted prior to legislation permitting the medically supervised use of cannabis in Spain, found that 52.6% of participants who did not currently use cannabis were aware it could help with the management of symptoms. In addition, 14.5% of this group stated it was because of the drugs illegality that the decision was made to avoid use. This reiterates that people are aware of the possible benefits but some are hindered from using due to fear of legal action. Furthermore, 83.4% of those who had never used cannabis stated they would support a future of legalisation. Martinez-Rodriguez (2008) also reinforced the potential dangers associated with using cannabis illegally. In the period when cannabis was illegal for medicinal use, participants reported that the most usual cannabis source was through people growing their own supply or obtaining from a friend or relative. It was found that when people were unable to grow their own controlled supply, for example due to a worsening in clinical symptoms or when they did not have someone to do this for them, there was the risk that that the individual would obtain and consume a non-reliable, un-controlled product. In summary, legal concerns are a strong deterrent for many people in different countries.

Discussion:

This literature review has found that people who choose to use cannabis for MS as a form of 'self-help', can face or fear social stigma (Bottorff et al, 2013; Page & Verhoef, 2006): similar to that described in the classic work of Goffman. Goffman (1963) contends that people can experience both internal and external stigma associated with a belief or behaviour, which lies outside the realms of normality, as defined by the majority. This causes an individual to be regarded as a rejected stereotype or undesired within the normal functioning of society (Goffman, 1963). A significant consequence for community nursing here is that people sometimes feel they cannot discuss or disclose cannabis use because of anticipated negative reactions and consequences on the relationship, although, cannabis has clear benefits for some (Zajicek et al, 2003; Trout & DiDonato 2015; Kindred et al 2017). This was also found to be the case in research carried out by the UK All Party Parliamentary Group (APPG) – but not retrieved in the search for this review. Findings showed 37% of people using cannabis for medical reasons did not discuss this with a healthcare professional, worryingly, 63% who had discussed cannabis use with their GP experienced a reciprocated negative attitude (28%), which, to some extent, is supported by the findings from this review.

Person-centred care requires community nurses to work in partnership with people, engaging in healthful relationships providing encouragement for active involvement and decision-making (QNIS, 2015). Therefore, community nurses require both sympathetic presence (McCormack & McCance 2017) and a professional understanding of the risks faced by persons with MS who use cannabis for symptom control, such as those stated in this review. In addition, they need to be aware that persons using cannabis illicitly may not immediately disclose that they are doing so when the nurse is undertaking assessments. The review has demonstrated that the community nurse could potentially face clinical dilemmas when working with people who use or are willing to use cannabis as a means of self-management (Farrell et al, 2014), therefore, problems may arise when aiming to offer person-centred care. The review has also shown that people strongly believe there are benefits cannabis may provide to help symptoms associated with MS. However, many remain fearful because of the drugs previous

legal status, and therefore, the ongoing debate of what is regarded as a medical product (GOV UK 2019). It is vital that community nurses hear these experiences in order to positively influence conversations when working with someone who uses cannabis for symptom relief in MS. This should promote a feeling of openness and honesty, allowing for meaningful conversation about cannabis use.

Community nurses should also be aware of any safety concerns to which patients may be exposed. For example, obtaining illegal cannabis from someone potentially entering the home and selling this to the person. Where there may be serious risk or actual harm, the need for safeguarding clearly challenges the boundaries to risk taking and to confidentiality (NMC Code of Conduct, 2015). Where community nurses are aware of cannabis use alongside other medications, this should be, with consent, appropriately recorded in the care record alongside a risk assessment and any advice or health promotion; consistent with NMC standard 18.3 (NMC Code of Conduct, 2015).

The MS Society has been vocal about decriminalising cannabis for people with MS and the Royal College of Nursing (RCN) also began to back the future for legalisation (MS Society, 2018; RCN 2018). This is highly relevant to community nursing due to recent drug policy reform and their close working relationship with persons living with MS.

Community nursing teams need to have discussions about their values and beliefs on this issue and on their responses when encountering the issue in practice, keeping central that providing person-centred care is encompassed by working with the person's values and beliefs and knowing what matters most to the person receiving care (McCormack and McCance, 2017). Drawing on research to provide evidence about the experiences of people with MS and their use of cannabis, can help community nurses to enter into more trusting and open relationships: an essential component of person-centred care.

Conclusion:

The literature review has found there is a clear need for nurses to hear and understand people's perceptions and experiences of using cannabis. Yet, it is apparent people may be un-willing to disclose cannabis use to friends, family and importantly, to community nurses due to social and potential legal repercussions and fear of disrupting relationships with community nurses. Nurses aspire to provide holistic and compassionate care which is ethically and legally sound. Cannabis use among people with MS may present a challenge to the nurse's way of working. Pre-understandings, values and beliefs should be brought to the forefront in order for nurses to critically reflect on and challenge non-person-centred care. It is clear there is an untapped potential for further research, but also importantly, in working openly with the person and valuing what is important to them.

Key points:

- People using cannabis for relief of symptoms of MS may fear stigma and judgement from others, including healthcare professionals, which may influence their willingness to disclose this to community nurses caring for them.

- There is poor evidence about community nurses' current perspectives and practices relating to cannabis use amongst persons with MS.

- Community nurses need to be open to the possibility that persons living with MS may use cannabis illicitly and seek opportunities for open dialogue.

- Further research examining the experiences of people who use cannabis for relief of MS and the approaches used by community nurses to support them is required to promote person-centred care.

References:

American Academy of Neurology (2014) *Summary of systematic review for patients and their families: medical marijuana in certain neurological disorders.* https://www.aan.com/Guidelines/home/GetGuidelineContent/650 (accessed 21/02/19).

Atakan Z (2012) Cannabis, a complex plant: Different compounds and different effects on individuals. *Therapeutic advances in psychopharmacology.* **6** (4): 241-54. doi: 10.1177/2045125312457586

Banwell E, Pavisian B, Lee L, Feinstein A (2016) Attitudes to cannabis and patterns of use among Canadians with multiple sclerosis. *Multiple sclerosis and related disorders.***10**: 123-26. doi: 10.1016/j.msard.2016.09.008. Epub 2016 Sep 28.

Barrus GD, Capogrossi LK, Cates CS, Gourdet KC, Peiper CN, Novak PS, Lefever WT, Wiley LJ (2016) Tasty TCH: promises and challenges of cannabis edibles. *National library of medicine.*

Bonn-miller OM, Boden TM, Bucossi MM, Babson AK (2014) Self-reported cannabis use characteristics, patterns and helpfulness among medical cannabis users. *The American Journal of drug and alcohol abuse.* **40** (1): 23-30.

Bottorff LJ, Bissell JLL, Balneaves GL, Oliffe JL, Capler RN, Buxton J (2013) Perceptions of cannabis as a stigmatised medicine: a qualitative descriptive study. *Harm reduction journal.* **10** (2): 1-10.

Carter N, Lukosuis BD, Dicense A, Blyth J, Neville J A (2014) The use of triangulation in qualitative research. *Oncology nursing society.* **41** (5): 545-57. doi: 10.1188/14.ONF.545-547

Chong MS, Wolff K, Wise K, Tanton C, Winstock A, Silber E (2006) Cannabis use in patients with multiple sclerosis. *Multiple Sclerosis 2006.* **12** (5): 646-51. doi.org/10.1177/1352458506070947

Farrell M, Buchbinder, R, Hall W (2014) Should doctors prescribe cannabinoids. *British Medical Journal.* **348.** doi: https://doi.org/10.1136/bmj.g2737

Fox EJ, Rhoades RW (2012) New treatments and treatment goals for patients with relapsing remitting multiple sclerosis. *Current opinion in neurology.* **25.** doi:10.1097/01.wco.0000413320.94715.e9.

George J, Martin F (2016) Briefing paper. Living with long term conditions. *British Medical Association.* file:///C:/Users//Downloads/Living-with-long-term-conditions%20(1).pdf (accessed 20/09/18)

Goffman E (1963) *Stigma notes on the management of spoiled identity.* Simon & Schuster Inc. New York

Goldenberg MM (2012) Multiple Sclerosis review. *Pharmacy and Therapeutics.* **37** (3): 175-84.

GOV UK (2018) *Government announces that medicinal cannabis is legal.* https://www.gov.uk/government/news/government-announces-that-medicinal-cannabis-is-legal. (accessed 26/02/19)

GOV UK (2019) *Cannabis-based products for medicinal use in humans: commission to the ACMD.* https://www.gov.uk/government/publications/cannabis-based-products-for-medicinal-use-in-humans-commission-to-the-acmd. (accessed 26/02/19)

Hornby P; Sharma, M (2010) Standardized cannabis in multiple sclerosis: a case report. *Journal cases.* doi: 10.1186/1757-1626-3-7

Kesserling J, Beer S (2005) Symptomatic therapy and neurorehabilitation in multiple sclerosis. *The Lancet.* **4** (10): 643-52. doi: org/10.1016/S1474-4422(05)70913-9

Kindred HJ, Li K, Ketelhut BN, Proessl F, Fling WB, Honce MJ, Shaffer RW, Rudroff T (2017) Cannabis use in people with Parkinson's disease and multiple sclerosis: A web-based investigation. *Complementary therapies in medicine.* **33**, pp 99-104.

Luoma JB, Kulesza K, Hayes CS, Kohlenberg B, Larimer M (2014) Stigma predicts residential treatment length for substance use disorder. *American journal of drug and alcohol abuse.* **40** (3) 206-212 doi: 10.3109/00952990.2014.901337

Martinez-rodrigues E J, Munteis E, Carreno M, Blanco Y, Roquer J, Abanades S, Graus F, Saiz A (2008) Cannabis use in Spanish patients with multiple sclerosis: fulfilment of patents expectations? *Journal of the neurological sciences.* **273** :103-7. doi: 10.1016/j.jns.2008.06.037

McCormack B, McCance T (2017) *Person-centred Nursing theory and practice.*: John Wiley & Sons Ltd. West-Sussex

Minagar A (2013) Current and future therapies for multiple sclerosis. *Scientifica.* doi: org/10.1155/2013/249101

MS Society (2017) *Cannabis and MS. Our report.* https://www.mssociety.org.uk/ms-resources/cannabis-and-ms-our-report (accessed 12/10/17)

MS Society (2017) *What is MS.* https://www.mssociety.org.uk/what-is-ms (accessed 12/10/17)

MS Society (2018) *Cannabis for MS: we've come far but there is still a way to go.* https://www.mssociety.org.uk/get-involved/campaign-with-us/campaigns-blog/cannabis-for-ms---we-have-come-far-but-there-is-still-a-way-to-go# (accessed 11/02/19)

MS Trust (2018) *Cannabis.* https://www.mstrust.org.uk/a-z/cannabis (accessed 13/02/19).

MultipleSclerosis.net (2018) *My experience with medical marijuana.* https://multiplesclerosis.net/living-with-ms/my-experience-medical-marijuana/ (accessed 13/02/19).

NICE (2014) *Multiple sclerosis in adults: Management.* https://www.nice.org.uk/guidance/CG186 (accessed 26/10/17)

NMC (2001) *Standards for specialist education and practice.* https://www.nmc.org.uk/globalassets/sitedocuments/standards/nmc-standards-for-specialist-education-and-practice.pdf (accessed 19/09/18)

NMC (2015) *The Code.* https://www.nmc.org.uk/standards/code/read-the-code-online/#fourth. (accessed 21/03/19).

Novick G (2008) Is there a bias against telephone interviews in qualitative research? *Research in Nursing and Health.* **31** (4): 391-98. dio:10.1002/nur.20259

Page A S, Verhoef J M (2006) Medical Marijuana use experiences of people with multiple sclerosis. *Canadian family physician.* **52** (1): 65-72.

Page A S, Verhoef J M, Stebbins A R, Metz M L, Levy C J (2003) Cannabis use as described by people with Multiple Sclerosis. *The Canadian Journal of neurological sciences.* **30** (3): 201-5.

Parliament UK (no date) *All Part Parliamentary Groups.* https://www.parliament.uk/about/mps-and-lords/members/apg/ (accessed 02/10/18)

QNIS (2015) *The QNI/QNIS voluntary standards for district nurse education and practice.* https://www.qnis.org.uk/wp-content/uploads/2016/11/DN-Standards-with-Endorsements.pdf (accessed 02/10/18)

Rajagopal S (2006) The placebo effect. *Psychiatric bulletin.* **30** (5): 185-88. dio:org/10.1192/pb.30.5.185.

Royal College of Nursing (2018) *RCN welcomes move to legalise medicinal cannabis products.* https://www.rcn.org.uk/news-and-events/news/rcn-welcomes-move-to-legalise-medicinal-cannabis-products (accessed 11/02/19)

Russo M, Naro A, Leo A, Sessa E, D'Aleo G, Bramanti, P, Calabro RS (2016) Evaluating Sativex in neuropathic pain management: a clinical an neurophysiological assessment in multiple sclerosis. *Pain medicine.* **17** (6) 1145-54 doi: 10.1093/pm/pnv080.

Satterlund TD, Lee PG, Moore SR (2015) Stigma among California's medical marijuana patients. *Journal of psychoactive drugs.* **47** (1) 10-7 doi: 10.1080/02791072.2014.991858

Saunders B, Sim J, Kingstone T, Baker S, Waterfeild J, bartlam B, Burroughs H, Jinks C (2018) Saturation in qualitative research: exploring its conceptualization and operationalization. *Quality and Quantity.* **52** (4): 1893-1907. dio: 10.1007/s11135-017-0574-8

Scottish Government (2016) *Quality strategy.*
https://www2.gov.scot/Topics/Health/Policy/Quality-Strategy (accessed 26/02/19).

Serpell MG, Notcutt W, Collin C (2013) Sativex long term use: an open-label trial in patients with spasticity due to multiple sclerosis. *Journal of neurology.* **260** (1) 285-95 doi: 10.1007/s00415-012-6634-z.

Sexton M, Cuttler C, Finnell S J, Mischley K L (2016) A cross-sectional survey of medical cannabis users: patterns of use and perceived efficacy. *Cannabis and cannabinoid research.* **1** (1): 131-38. dio: 10.1089/can.2016.0007

Skovgaard L, Nicolajsen H P, Pedersen E, Kant M, Fedrikson S, Verhoef M, Meyrowitsch W D (2012) Use of complementary and alternative medicine among people with multiple sclerosis in the Nordic countries. *Autoimmune disease.* 1-13. dio: 10.1155/2012/84108

Sleeper AJ, Boxhain SS (2013) Stigmatization by nurses as perceived by substance abuse patients: A phenomenological study. *Journal of nursing education and practice.* **3** (7) 92-98. Dio: 10.5430/jnep.v3n7p92

Torjesen I (2018) Medical cannabis to be prescribed. *British medical journal.*
https://www.bmj.com/bmj/section-pdf/982051?path=/bmj/362/8163/This_Week.full.pdf (accessed 26/02/19)

Troutt D W, Didonato D M (2015) Medical cannabis in Arizona: patient characteristics, perceptions, and impressions of medical cannabis legalisation. *Journal of psychoactive drugs.* **47** (4): 259-66. dio: 10.1080/02791072.2015.1074766

Zajicek J P, Fox P J, Sanders P H, Wright E D, Vickery J P, Nunn J A, Thompson J A (2003) Cannabinoids for treatment of spasticity and other symptoms related to multiple sclerosis (CAMS study): multi-centre randomized controlled trial. *The Lancet.* **362:** 1517-26. dio: https://doi.org/10.1016/S0140-6736(03)14738-1

Zajicek J P, Sanders P H, Wright E D, Vickery J P, Ingram M W, Reilly M S, Nunn J A, Teare J L, Fox J A, Thompson J A (2005) Cannabinoids in multiple sclerosis (CAMS) study: safety and efficacy data for 12 months follow up. *Journal of neurology, neurosurgery and psychiatry.* **76** (12).

Zajicek JP, Hobart JC, Slade A, Barnes D, Mattison PG (2012) Multiple sclerosis and extract of cannabis: results of the MUSEC trail. *Journal of neurology, neurosurgery and psychiatry.* **83** (11) 1125-32. doi: 10.1136/jnnp-2012-302468

Appendix 1. Table of Literature

Author, year, country, setting	Purpose	Sample size	Type of research	methods	Inclusion/exclusion	limitations	Findings/results
Banwell et al, 2016, Canada. Participants recruited at a Neuropsychiatry clinic and a neurology clinic.	To investigate patterns of use among people with MS and their attitudes towards cannabis.	225, males and females.	Quantitative	Questionnaire containing yes/no answers. Broken into 3 categories; demographic and neurological status, cannabis use and attitudes towards cannabis. Study was not explicit in describing data analysis.	*Inclusion*- diagnosis of MS, *Exclusion*- intellectual disability.	Self-reporting system which could be open to bias. This could have been likely among participants who were reporting symptoms associated with mental health.	44 people (19.5%) currently use cannabis with smoking being the most favoured route. Men being more likely to use (p=0.007).Participants with higher level of education were more likely to believe cannabis could cause harm medically (p=0.006). Subjects who reported using anti-anxiety medication were more likely to disclose cannabis use (p=0.004). **Attitudes towards use-** 122 participants approved of cannabis (54.3%) and 75 were neutral (33.2%). 98

							participants (43.7%) in favour of legalisation for medical use. 198 participants viewed the drug as helpful (87.6%) rather than harmful 108 (47.9%. 32 participants (14.1%) stated their feeling toward a friend would change if they were using cannabis and 110 (48.8%) stated they would be upset if a loved one was using cannabis. 64 participants (28.6%) sated they would feel uncomfortable if someone was using it around them.
Kindred et al, 2017, USA. Participants were recruited online through an anonymous online hyperlink posted to recruitment	To assess cannabis use in Parkinson's disease (PD) and MS and compare results of self-reported assessments of neurological	595 included, males and females. 76% of people reported PD and 24% reported having MS.	Quantitative	Online survey posted to the Michael J Fox Foundation and the national multiple sclerosis society webpages from 15 Feb to 15 Oct 2016. survey collected demographics, cannabis use	No inclusion or exclusion criteria. Anyone who had access to the internet could have participated.	Self-reporting system which could be open to bias. Sample was limited to people who have access to the internet and one must be familiar with online tools.	**Cannabis use-** 44% of participants reported to be current users and 74% of this sample stated their use was for medicinal purpose. Only 42% reported owning a medical cannabis card. MS participants

pages of 2 websites.	disability between current users and non-users (Non-users regarded as those who were not using cannabis at present and included people who have used it in the past).			information, it used standardised questionnaires to assess neurological function, fatigue, balance and physical activity participation. (Guys neurological status scale (GNDS), Nottingham Health profile (NHP), fatigue severity scale (FSS), Activities of balance confidence (ABC), and the international physical activities questionnaire (IPAQ)). Data were analysed using chi square tests.		Cannot verify legitimacy of user's diagnosis.	were more likely to have used cannabis in the past and also be current users respectively (p=0.001; p=0.001) also more likely to report the reduction of prescribed medication with cannabis use (p=0.001). **Self-reported scales-** no correlation was found between disease diagnosis and cannabis use for any of the GNDS, NHP, FSS, ABC or IPAQ values (p=0.05), suggesting that differences between users and non-users were not due to disease diagnosis. Current cannabis users had lower sores on self-reporting scale GNDS (p=0.006) specifically within the memory (p=0.030) mood (p=0.002) and

							fatigue (p=0.009) sections.
Zajicek et al, 2003. Undertaken on an out-patient basis at 33 neurology and rehabilitation clinics across the UK	The aim of the study was to test the notion that cannabinoids have a beneficial effect on spasticity and other symptoms associated with MS.	630 participants with stable MS, males and females.	Quantitative	630 patients treated at 33 UK centres with oral cannabis extract (n=211), tetrahydrocannabinol (THC) (n=206) or a placebo (n=213). Trail duration was 15 weeks and the primary outcome measure was a change in overall Ashworth score. Analysis was by intention to treat. Secondary measures were the Rivermead mobility index (RMI), a timed 10m walk, and 4 self-completion questionaries'-the United Kingdom neurological disability score (UKNDS), the Barthel index, the general health questionnaire (GHQ-30) and a series of 9 category rating scales.	*Inclusion-* Those with a clinically definitive diagnosis or laboratory-supported MS who had had stable disease in the prior 6 months and lead up to study, with an Ashworth score of > 2 in two or more lower limb muscle groups. Over 18 years of age *Exclusion-* any participant with ischaemic heart disease, those with active sources of infection and those currently taking medication which could affect spasticity, fixed tendon contractures, severe cognitive impairment, PMH of psychotic illness, major illness in any other body area,	The risk of unmasking among groups and assessors. Capsules could not be made identical so each had a matched placebo. 38 patients withdrew from study post randomisation due to multiple reasons listed within paper.	611 patients were followed up to the end of the study (lost participants through discontinuation choice and deaths) The study discussed no treatment effects of the cannabinoids against the primary outcome (p=0.40) the estimated mean reduction in overall Ashworth score for participants taking cannabis extract compared with those in the placebo group was 0.32% and 0.94% in those taking THC compared with placebo. There was evidence in patient reported spasticity and pain (p=0.003) 61% of cannabis extract group, 60% in the THC group and 46% in placebo.

					pregnancy and any anyone who has used THC at any time and the use of cannabis within the 30 days leading up to commensal of study.		
Bottorff et al, 2013. Canada. Patients recruited from 4 British Columbia community-based cannabis dispensaries and also through an online forum for medicinal cannabis users from 2007-2008.	Aim of the study was to describe cannabis user's perceptions of and responses to stigma attached to using medical marijuana.	23 participants, 13 women and 10 men. Two transgendered females were included in the women's group (Male to female transgender). 2 participants had neurological conditions (did not specifically state which) and 4 participants reported having 'other'.	Qualitative	Utilising qualitative methodology, inductive analysis and purposive sampling in depth accounts could be drawn using semi structured interviews. These were face-to-face or over the phone interviews and participants were encouraged to speak about their beliefs and experiences of stigma. This was conducted at a time and place which was suitable for the participant. Interviews were conducted by trained research assistants and lasted around 1-	*Inclusion*-reported cannabis use in the last 30 days and for over 6 consecutive months, over the age of 19 to participate and English speaking. *Exclusion*- under the age of 19 and no reported cannabis use	Experiences of and reactions to cannabis use could have differed if participants had been recruited from more conservative regions, this was due to the study being conducted in an area known for its illegal cannabis production and tolerance on recreational use. Most participants declared they were long term users making the choice to use cannabis for medical reasons	Participants experience of stigma was related to negative views of cannabis as a recreational drug, using cannabis in the context of stigmatising vulnerability and criminal punishments associated with the drug. There were a number of strategies people used to try and manage stigma; conceal their medicinal cannabis use from others so they wouldn't face external stigma, educating those who did not approve about the associated benefits it has for

				3 hours. A short questionnaire was administered to those taking part requiring details of demographics, history of cannabis use and information regarding health issues which have influenced using medical cannabis.		several years ago, therefore their experiences of stigma may differ from those who have just begun using. Due to purposive sampling it could be said that those who had experienced more negative stigma and who had made a decision to stop using for fear of its social and political ramifications are likely to be underrepresented in this study.	them and their condition and lastly being responsible with their cannabis use.
PAGE&VERHOEF, 2006. Canada. Participants were recruited for the study through a mailed survey to 780 patients from the MS clinic database in Calgary, Alta. Potential	Aim of the study was to describe medical marijuana use from the perspectives of patients with multiple sclerosis.	6 men and 8 women with multiple sclerosis were recruited.	qualitative	Participants identified themselves to the researcher after receiving an invitation in the original mailed survey. Eligibility was confirmed and purposive sampling was used to recruit participants. Semi-	*Inclusion-* over 18 years of age, and clinically definitive diagnosis of MS or laboratory supported. *Exclusion-*under the age of 18	The study did not discuss any limitations and no limitations were documented.	Descriptive accounts fell into 3 broad areas: patterns of use, legal and social concerns and perceived effects. Cannabis use patterns ranged from little use to very regular use and this was said to be

interviewees responded to the interview invitation within the survey.				structured interviews were conducted by the first author. An interview guide was created which drew from the medical literature, media and written comments within the original survey. The interview guide was reflected these variables but was very flexible which allowed for participants to speak freely. Interviews were all tape recorded and transcribed with participants permission. Participants could withdraw from the study at any time and were also given the option to withdraw information from the tape recordings.			influenced by supply, social factors and symptoms. Social concerns were centred around those who has disclosed their use of the drug. The perceived benefits were reductions in pain, spasms, spascitity, nausea, numbness, sleep problems, bladder and bowel problems, fatigue. Some reported it helped with being able to write, eat and drink and also with sexual functioning. There were a small number of side effects identified such as: a feeling of being 'high', problems with cognition and balance. It was noted that although there are a small number of associated side effects the benefits the patients gained

							made the risk acceptable.
Maertinez-Rogrigues et al, 2008. Spain. participants recruited from two hospitals in Spain.	The aim of the study was to evaluate the prevalence of cannabis use, related factors and degree of satisfaction in Spanish patients with a diagnosis of MS prior to the establishment of medically supervised use.	175 participants males and females	Quantitative	Cross sectional questionnaire based surveys were handed out during routine medical visits to consecutive patients in two university based neurology clinics. The questionnaire contained 56 detailed questions. Patients were assessed for their expanded disability status score (EDSS), progression index, multiple sclerosis severity score (MSSS) and the type of MS the patient was living with. Patients were classified as cannabis non-users, recreational users and medical users. The questionnaire was taken home with the patient to complete and then returned to the	*Inclusion-* adult patient (did not specify exact age) and a diagnosis of MS based on McDonald Criteria. *Exclusion-* there were no exclusion criteria with the exception of moderate to severe cognitive impairment.	The study did not discuss any limitations and no limitations were documented.	Of the 175 patients who returned the survey, 145 Patients reported non-medical use (recreational) and 30 reported medicinal use. At the time of the study cannabis was being used by 56.7% (17/30) of medicinal users. First cannabis consumption was after a diagnosis of MS in 15 (50%) of medical users. An improvement in symptoms was reported by 14 (46.7%) medical users. Awareness of cannabis' potential as a medicine, smoking use, pain, higher disability and lower age were all independently associated with medical use. It was also reported that most patients would

				centre in a pre-paid envelope. Statistical analysis was undertaken once all data was collected.			support legalisation for medicinal use and were willing to receive cannabis under medical control if legalised (83.4% of never-users and 94.5% of users (p=<0.05).
Troutt&DiDonato, 2015. USA. Participants recruited from medical cannabis dispensaries located throughout Arizona	Aim of the study was to discover patient characteristics, perceptions and impressions of medical cannabis legalisation. The study aimed to gauge how patients felt prior to medical legalisation and how they feel about it now.	367 participants. Males (63.8%) and ranged from 18-83 years of age. 5 participants had MS and 130 participants experienced muscle spasms.	Quantitative	To protect confidentiality researchers approached dispensary owners for assistance in recruiting participants. Owners informed patients of the study and those interested were directed to a website which contained information on the study and patient's rights if they chose to be involved. If the patient agreed to participate they checked a box and the survey questions appeared. Patients were asked about their condition,	*Inclusion*- no inclusion criteria specified *Exclusion*- no exclusion criteria specified	Due to recruitment taking place within cannabis dispensaries there could be an element of positive bias among those patients who use cannabis medically. Also, individuals who use cannabis as a means of medication and self-management but for whom cannabis is not effective were unlikely to participate.	**Perceived effectiveness of medical cannabis-** in relation to participants with MS and muscle spasms it was found that 100% of participants with MS experienced general relief from using medical cannabis, 75% had relief compared to other medications and 33.30% of MS participants were using other medications less frequently. 76.20% Participants with muscle spasms noted general relief from cannabis use and 75% experienced relief

				patterns and methods of cannabis use and perceptions of prior medical cannabis users. Each theme contained additional questions which were answered on a five-point Likert type scale e.g. degree of relief experienced overall from consuming cannabis (1= no relief at all and 5=almost complete relief). Did not discuss method of data analysis.			compared with other medications and 91.40% of participants were using other medications less frequently. 89.1% of patients reported that acquiring cannabis after legalisation felt *'somewhat safer or much safer'* and 85.4% reported that they had *'somewhat more confidence or much more confidence'* in knowing they were purchasing a safe and uncontaminated product. 79.5% reported that the medical cannabis was *'somewhat more effective or much more effective'* in treating their conditions. Over 30% of patients used cannabis around once per day and the preferred method of

							consumption was smoking with around 40% of participants.
Page et al, 2003. Canada. Participants were recruited from Calgary MS clinic database.	The aim of the study was to describe cannabis use among this patient group including information on people's beliefs, practices and experiences related to use.	Survey was returned by 420/673 eligible participants. 26% males and 74% females.	quantitative	Survey was mailed to a possible total sample of 780. 107 were undeliverable due to moving home or were deceased. 673 eligible candidates and survey was returned by 420 in a pre-paid envelope. Questions within the survey were primarily close-ended but there were some opportunities for participants to provide additional detail if answers were not applicable to them on that particular question. Participants were asked about sociodemographic information (age, sex marital status, level of education) and information on disease	*Inclusion*-did not specify inclusion criteria *Exclusion*- patients for whom an address was not known and those who had not given blanket consent to be approached for research. Those under the age of 18 were excluded as those with probable MS and not clinically definitive or laboratory supported.	Data gained was subjective and must be interpreted cautiously.	72% of respondents stated that it should be legally permissible for people to use cannabis for medical reasons, 23% had no opinion while 5% opposed. 96% stated they were aware of cannabis and its potential therapeutic benefits. Reasons given for not using cannabis by those who were aware of the potential benefits but who have not tried it (n=222) were: it's an illegal substance (64%), concern surrounding side effects (34%), lack of knowledge on how to obtain it (34%) and the disbelief it would help alleviate symptoms. A total of 176 patients had reported trying cannabis with 67 for

					characteristics (medication use, MS diagnosis and onset, pattern, disability and symptom experience. Questions on cannabis use included; reasons for use, patterns of use and perceptions of effects. Data were analysed in STATA 6 computer programme to summarise responses. Content analysis was used to describe the textual comments.			medical purposes. 43 people had used it within the past 3 months for symptom relief and 24 people had discontinued use. Reasons for discontinuation were cost (n=11) side effects (n=10) legal concerns (n=8) and lack of effectiveness (n=7). Multiple regression showed that education level, marital status and use of conventional medication were not factors which influenced cannabis use. However, sex, age, level of income and level of disability were all influencing factors for use. Comments were made from 35 participants within the study ranging from cannabis effect and reasons for use/ non-use.

Chong et al, 2006. UK. Participants were recruited from neurology outpatient clinics at 2 hospitals in London and 1 in Kent.	The aim of the study was to describe the extent and patterns of cannabis use among MS patients in South-East London and surroundings.	Questionnaires completed by 254/337 MS patients. Males and females.	quantitative	Patients with a diagnosis of MS who attended the neurology departments at either Kings College Hospital, Queen Elizabeth and the Medway hospital were given a self-reported questionnaire. This was piloted in a local MS support group before administration to potential participants. The questionnaires included demographic details, MS history including disease duration and disability using the Guys Neurological Disability Scale. Patients were asked about current and previous use and other recreational drug use. A list of symptoms was included and patients	Inclusion- did not specify inclusion criteria Exclusion- patients under the age of 18, those with severe mental health problems and those who were unable or unwilling to give consent were all excluded from the study.	Due to the self-reporting nature of the questionnaire results may not be reliable and data yielded subjective results which must be applied cautiously.	Total response rate of 75%. 43% of patients reported using cannabis at some stage in their life (ever-users) of these 68% (75/110) had used cannabis to help symptoms. 46 participants (18%) had used cannabis in the last month (current users) of whom 12% used cannabis for symptom relief. Increasing disability, tobacco smoking, marital status were all independent factors which influence MS related cannabis use. Cannabis use was more common among patients who were chair-bound compared to those who could walk unaided. 71% of patients when asked said they would try the drug if it was

				were asked about the perceived efficacy of cannabis in trying to manage these. Those would had used cannabis at least once were described as 'ever-users', those who were using cannabis at least once a month and at the time of the survey were described as 'current users'. MS related cannabis use was described as individuals who reported that they had not used cannabis before they were diagnosed with MS and they had only stared using it because of MS or those who would not use cannabis if they did not have MS. Data were analysed using SPSS and STATA. Comparison was made between MS related use and			available to them on prescription.

				the rest of the group (non-users and recreational users).			